



The Arc[™]
New Mexico

Monthly Memo
June, 2012

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The mission of The Arc of New Mexico is to improve the quality of life for individuals with developmental disabilities of all ages by advocating for equal opportunities and choices in where and how they learn, live, work, play and socialize. The Arc of New Mexico will promote self-determination, healthy families, effective community support systems and partnerships.

“Empowerment in Action”

Marty Ford, Chief Public Policy Officer
The Arc of the United States
Washington, D.C.
Saturday Morning Plenary Speaker



**June 22-23, 2012
Crowne Plaza Hotel
Albuquerque, New Mexico**

Sponsored by The Arc of New Mexico, The New Mexico Developmental Disabilities Planning Council, the New Mexico Department of Health Developmental Disabilities Supports Division and United Healthcare

NM HSD Announces Public Hearings about Centennial Care

The State of New Mexico Human Services Department (HSD) announced that it is seeking additional public input and comment on the submission of the Centennial Care 1115 demonstration waiver to the Centers for Medicare & Medicaid Services (CMS).

“With the initial submission of our waiver to CMS, we have seen the opportunity to seek out further input from New Mexicans on our work on Centennial Care,” said Sidonie Squier, Secretary of the Human Services Department. “This input will help us further shape the future of a sustainable Medicaid program to provide services to those most in need while avoiding cuts in the program. It will also help guide our discussions with the federal government as approval of the waiver progresses.”

New Mexico is in the process of modernizing the Medicaid program to ensure its sustainability into the future. New Mexico intends to do that through a request of the 1115 Demonstration Waiver that will result in Centennial Care, which will continue delivering benefits for those most in need, now and into the future, while avoiding cuts. Centennial Care 1115 Demonstration Waiver will result in:

- Maximizing chances of a healthier population
- Purchasing quality care rather than quantity of care
- Slowing the rate of growth of the program costs by maximizing administrative simplicity and focusing on better outcomes, and
- Requiring that plans, providers, recipients and the State all move together to slow the rate of growth of the cost of the program while avoiding cuts, improving quality, and
- modernizing our Medicaid system.

The State’s full public notice, which describes the Centennial Care Demonstration Waiver proposal in more detail, can be found on the HSD website at

<http://www.hsd.state.nm.us/Medicaid%20Modernization/index.html>.

The State continues to solicit comments on the Centennial Care Demonstration Waiver with several options for interested parties to submit comments.

- E-mail: Medicaid.Comments@state.nm.us
- Phone: 1-855-830-5252
- Regular Mail: Centennial Care comments – Human Services Department P.O. Box 2348,
- Santa Fe, New Mexico 87504

HSD will hold two public hearings, another Medicaid Advisory Committee (MAC) meeting, and will present before the Legislative Health and Human Services (LHHS) Committee to solicit comments from interested parties on the Centennial Care Demonstration Waiver on:

Date: Monday, June 25, 2012

Time: 1:00 p.m. to 5:00 p.m.

Location: Santa Fe

Legislative Health and Human Services Committee
State Capitol, Room 307 Corner of Old Santa Fe Trail
and Paseo de Peralta, Santa Fe, New Mexico

Date: Tuesday, June 26, 2012

Time: 1:30 p.m. to 4:00 p.m.

Location: Albuquerque UNM Continuing Education Building
1634 University Blvd. NE, Auditorium
Albuquerque, New Mexico

Date: Wednesday, June 27, 2012

Time: 10:00 a.m. to 12:30 p.m.

Location: Las Vegas Las Vegas Middle School - Lecture Hall
947 Old National Road
Las Vegas, New Mexico

Date: Monday, July 16, 2012

Time: 1:00 p.m. to 5:00 p.m.

Location: Las Cruces NM Farm & Ranch Heritage Museum
4100 Dripping Springs Road – Ventanas Room
Las Cruces, New Mexico

Webinar and/or teleconference details will be forthcoming, and will be posted on the Centennial Care page of the HSD website at www.hsd.state.nm.us as well as the state website at <http://www.newmexico.gov/>.

If you are an individual with a disability and require an accommodation to participate in the meeting, please call (505) 827-6245 or email Betina.McCracken@state.nm.us as soon as possible.

Clarification re The Arc's Position Statement on the SIS

The Supports Intensity Scale (SIS) is reported as a valid and reliable assessment tool, specifically designed to measure the type of support, frequency of support, and intensity of support an individual needs to fully participate in community life. The SIS was designed primarily as a person centered planning process.

Since its publication in January 2004, SIS is being used across the U.S. and abroad by service providers and agencies. The SIS was normed over 2 years on 1,308 people with varying degrees of intellectual disability from the ages of 16-72 within the United States and two provinces in Canada. Currently it is also being used in several states to inform and improve resource allocation decisions.

In New Mexico the SIS is part of an effort by the Department of Health (DOH) to maintain person centered supports while improving the overall cost effectiveness of the Developmental Disabilities (DD) Waiver program. The SIS Pilot Project included 500 interviews and was completed on September 2, 2011. In August 2011 the SIS became mandatory for all individuals being served on the DD Waiver. The information gathered from the SIS will provide the Developmental Disabilities Supports Division (DDSD) with the ability to fairly and equitably develop budgets to meet the needs of individuals with developmental disabilities in New Mexico.

Major concerns with SIS in New Mexico are that individuals who have participated in the SIS receive a score but do not receive any feedback that can help them with future planning and some individuals have indicated that the process has taken too long, was very strenuous and that the questions were too personal.

The Arc's Position

- The DD Waiver is intended to provide supports and services to individuals to help them live as active and contributing members of their communities.
- *The DD Waiver was never intended for individuals to buy an entire life.*
- The Arc supports the DOH's goal to improve the overall costs of the DD Waiver program while individuals receive appropriate supports and services according their unique needs and choices.
- The Arc supports DOH's use of a nationally normed assessment tool to fairly and equitably develop budgets to meet the needs of individuals with developmental disabilities in New Mexico.
- Individuals who participate in the SIS should receive timely feedback that can help them with future planning and an opportunity to appeal their scores if they do not reflect their needs.

Clarification: The Arc received several inquiries regarding the highlighted statement above. Our position is that the Home Based and Community Waivers were intended to provide a level of support that enables individuals to remain in the community along with other natural and community supports. The statement does not mean that individuals, once approved and receiving services, would be removed from services after a certain period of time.

Frequently Asked Questions About the SIS

New Mexico SIS Update

5-24-2012

Frequently Asked Questions

(Taken from the New Mexico Department of Health/DDSD Website)

1. How soon after I get my SIS assessment, can I expect to receive my score? DDSD has sent out approximately 1,300 SIS assessment packets, which include the NM SIS Report, Cover Letter with assessed NM SIS Level, and informational material on the SIS, including who to call with questions. These packets have been sent to each individual's case management agency for review with the individual/guardian, and distribution to the individual's interdisciplinary team. After the initial distribution of SIS results April of last year through March 2012, SIS

assessment results and reports are printed as they are received from the American Association of Intellectual and Developmental Disabilities (AAIDD), the SIS assessment contractor.

2. If individuals or guardians have questions, whom should they call? Each regional office has identified DDS staff to assist with questions regarding the SIS. These individuals are listed on the SIS Cover Letter in each SIS Results Packet.

3. If individuals or guardians want another SIS assessment, what is the process to obtain one? Each regional office has a log, which should be filled out and sent upon request to the DDS Central office for forwarding to AAIDD. There are some requirements for this request to be processed:

a. The Individual and/or Guardian must have received and reviewed the entire NM SIS Results Packet with their case manager prior to this request.

b. Only the Individual and/or Guardian can make this request.

4. How long will it be before I can have a second SIS assessment? DDS is developing a process for scheduling re-assessments while continuing to ensure everyone has an initial SIS within the timeframes for their annual planning process.

5. My annual ISP in November- when should I be receiving my SIS assessment? SIS Assessments are being scheduled for each individual, at least two months prior to their annual planning meeting. However, these timeframes may vary because of scheduling issues and other factors. AAIDD Schedulers are working with providers in each region to schedule SIS assessments.

6. Is it possible to get a copy of the NM SIS Report in Spanish? And my I have a translator at my SIS assessment? Yes, this is available. Please request this at the time you are contacted to schedule your SIS Assessment.

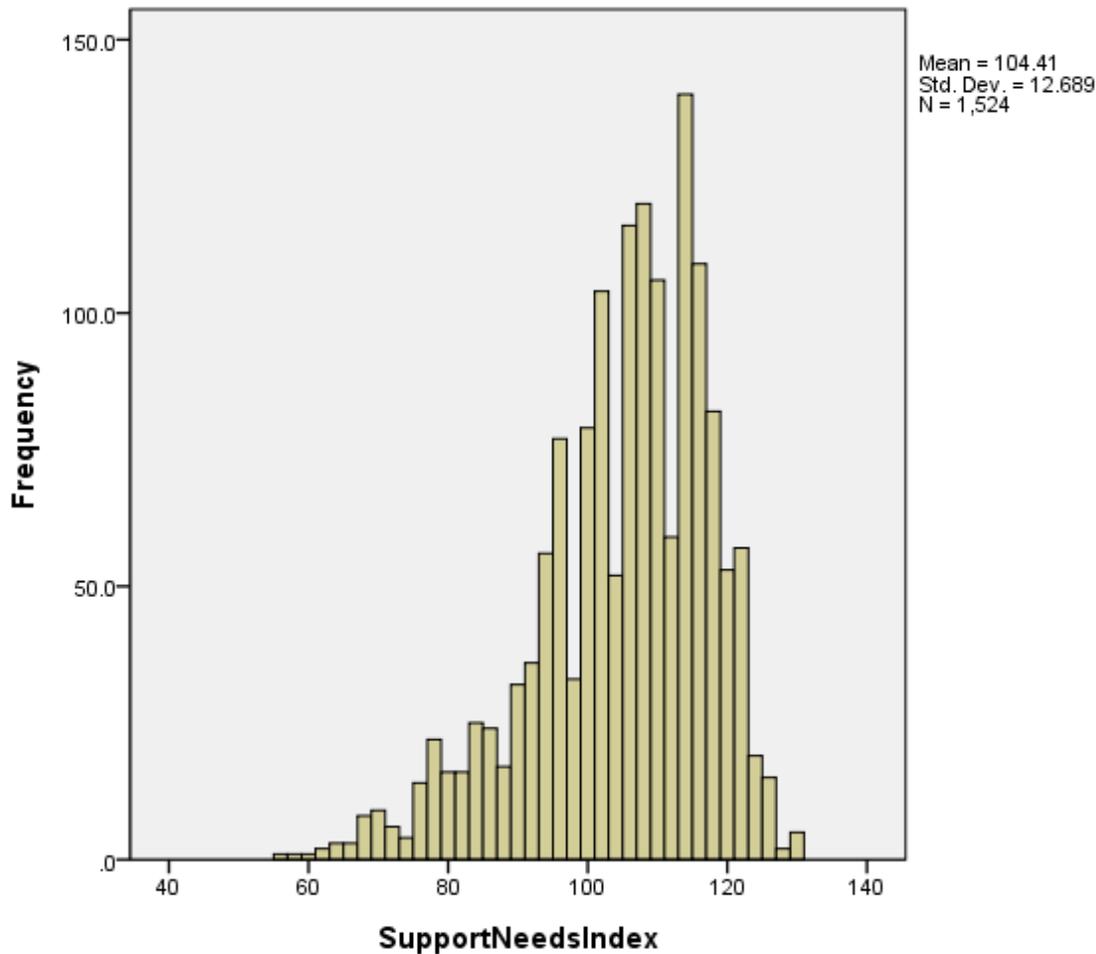
7. How are NM SIS Levels determined and what is their relationship to SIS Assessment Scores? When the project was initiated the decision was made to use a standard model that has been used and verified in other states. There is not a specific New Mexico algorithm, although we did modify the model to reflect New Mexico specific issues. HSRI's use of SUM ABE 3a and 3b to determine Group placement is widely documented in papers and in the NM SIS Pilot report. The chart below shows the current ranges used for NM Group assignment:

Groups	SIS ABE National Percentile	Section 3A Medical Support Score	Section 3B Behavior Support Score
A: Mild Support Needs and Low to Moderate Behavioral Challenges	25th percentile or less	≥ 0 to ≤ 6	≥ 0 to ≤ 6
B: Low to Moderate Support Needs and Behavioral Challenges	26th to 50th percentile	≥ 0 to ≤ 6	≥ 0 to ≤ 6
C: Mild to Above Average	1st to 75th percentile	≥ 0 to ≤ 6	≥ 7 to ≤ 10

Support Needs and Moderate to Above Average Behavioral Challenges			
D: Above Average Support Needs and Mild to Above Average Behavioral Challenges	51st to 75th percentile	≥ 0 to ≤ 6	≥ 0 to ≤ 6
E: High Support Needs and Mild to Above Average Behavioral Challenges	76th percentile or greater	≥ 0 to ≤ 6	≥ 0 to ≤ 10
F: Extraordinary Medical Challenges	Any	≥ 7 to ≤ 32 or Extraordinary medical risk	≥ 0 to ≤ 10
G. Extraordinary Behavioral Challenges	Any	Any	≥ 11 to ≤ 26 or Dangerousness to others or Extreme self injury risk

8. Can I get a copy of my “raw scores?” DDSD has received several requests asking for the “raw scores,” however, the results for each section of the SIS assessment are contained in the NM SIS Report. The “raw data” is provided in the numbers in the table titled “Activities Subscale Total Score by Area,” under the column marked “Total” in each report. These are the total raw scores.

9. What are the results so far for New Mexico? What NM SIS Levels are people being assessed at? The NM SIS Results for the 1,528 people assessed as of our last report fall into roughly the same “bell-shaped curve” as is distribution for other states where the SIS is used. The graph below describes this range of SIS Scores:



10. Can a therapist bill for attending a SIS evaluation? Therapists cannot bill to attend a SIS evaluation. In the rate structure for the 2012 DD Waiver, participation in assessments conducted by others is a productivity adjustment that amounts to 26 hours/year across their caseload so they need to make that amount last for doctor's appointments, swallow studies, SAFE or input to a BSC assessment or whatever. If therapists do agree to participate in a SIS, they would need to stay for the entire SIS session which would eat through the productivity adjustment pretty fast if they do more than a few. Therefore they must really prioritize if they get a lot of invitations. Cathy Stevenson, DDS Director, has stated that under the 2007 DD Waiver we are not considering participation in SIS to be billable time since therapy participation is not considered to be essential to the SIS completion.

11. When does a SIS trigger for a verification review and who does it? When the SIS group placement with and without Supplemental questions do not agree, a review is conducted. This review is conducted by a multidisciplinary team of DDS staff and consultants representing Nursing, Psychology, Therapy, Employment and DD generalists. The multidisciplinary team reviews the SIS answers related to supplemental questions along-side documentation from the individual's records, including at least the ISP, Therap, eChat, Health Trackers Data and other relevant sources such as Nursing or BSC quarterly reports, assessments, Health and Physical exam, and IDT minutes. This information, which includes at least three other sources of documentation, is used to assign a final SIS category.

Judge Rules for Community Living in Virginia

From Jamie Liban, Executive Director, The Arc of Virginia

A heartfelt **THANK YOU** to the many self-advocates, family members, providers and concerned citizens who came out to show support for the DOJ settlement agreement at the U.S. v Virginia Fairness Hearing yesterday. The courtroom was overflowing with people wearing “I support the agreement” stickers and their presence was certainly felt on this historic day in the ID/DD civil rights movement. As you may have read in [today’s headlines](#), **Judge Gibney announced he will approve the settlement agreement**. This is a significant development in Virginia’s transition to a community-based system of support.

The day began with the Judge providing background on the hearing, thanking those in attendance for their participation in the process and noting that he had received hundreds of letters from individuals who are affected by the proposed consent decree. After each party made their opening remarks, the Judge asked Mary Ann Bergeron, Executive Director of the Virginia Association of Community Services Boards (VACSB), to testify about the agreement as his expert. Mary Ann provided background on the role of CSBs and discussed how a transition to community-based care is possible when the right supports are in place. She also described how the system has been challenged by a lack of services for the thousands of families requesting community-based care who have been placed on growing waiting lists for Intellectual Disability (ID) and Developmental Disability (DD) Waivers.

Each party was then allowed 90 minutes to present a maximum of three witnesses per party and for cross-examination.

The U.S witnesses included a family member, a private provider and a well-known and respected expert in the field of developmental disabilities. Shareen Young-Chavez, the mother of an 18-year old with a significant developmental disability and complex medical support needs, testified about her experience on a waiting list and what a difference community-based services have made for her son and his family. Lisa Poe, Executive Director of Richmond Residential Services, testified about her agency’s history successfully serving people who have transitioned from institutions to community-based care, many of whom have complex support needs. Robert Gettings, the former Executive Director of the National Association of State Directors of Developmental Disability Services (NASDDS) and a Virginia resident, testified about how the majority of the country is far ahead of Virginia in its transition to community-based care, also explaining how such a transition is possible for the Commonwealth and why it is needed.

Virginia’s witness was James Stewart, Commissioner of the Virginia Department of Behavioral Health and Developmental Services. Commissioner Stewart discussed why a transition to community-based care is the right public policy for the

Commonwealth. The Commissioner provided an overview of the costs of institutions versus community-based care and said that when the Training Centers were created in the 1970's, the intention was that they be temporary and transitional in nature. He described how the census at state Training Centers has declined dramatically over the years, meanwhile thousands of people with intellectual and developmental disabilities who request community-based care are currently in waiting status. Commissioner Stewart stated that the Commonwealth is committed to a successful and responsible transition to community-based services and will use individualized planning and person-centered practices throughout the transition process.

Finally, the Intervening party (the 13 guardians who oppose the agreement) called witnesses who it deemed as experts. One was a psychiatrist, Dr. Adam Kaul of Midlothian, who expressed concern for people with intellectual disabilities who also experience mental illness, noting that they face increased risk of institutionalization. He also said that he felt psychiatric services and crisis intervention are more available in the training centers than in the community. When cross-examined by the U.S., Dr. Kaul stated that he believes these individuals can live successfully in the community if the right supports are in place prior to the individual's transition to the community. The next witness was Ted Campbell, a Director of Adult Protective Services in Lynchburg, who discussed the need for adequate oversight and protections in the community. Under questioning from the judge he acknowledged that the lowest percentage of reports of abuse and neglect were from group homes and community settings. While under cross-examination, Mr. Campbell said that he was unaware of the multiple layers of oversight that were required by the agreement. Finally, Robert Anthony, whose stepson lives in a Training Center, testified that he didn't agree with the costs of Training Centers and community-based services that had been cited by the state. Despite the fact that the costs of Training Centers and Medicaid Waivers are well documented in the state budget, he argued aggregate costs of community-based services may exceed those of Training Centers.

After 6.5 hours of testimony and closing arguments from each of the parties, Judge Gibney announced that he would approve the settlement agreement. **He said the agreement was lawful, fair, equitable, and consistent with public policy and not the product of collusion.** "Virginia has ... made an ideological and political decision. But that's their right," said Judge Gibney. "The public policy is what the Commonwealth decides and the public policy is that we want people with disabilities out in the community."

Judge Gibney also said before he would approve the agreement, he wants the parties to agree to some changes. The proposed changes would consist of the following: (1) a requirement that a death of any individual who has left a Training Center be immediately reported to the Independent Reviewer, (2) a clarification about who has the ability to provide consent for discharge from a Training Center and a requirement that consent must be provided prior to discharge (3) a provision reflecting the state

law that provides for a Training Center resident to receive services in a ICF/DD that is operated by the Commonwealth.

Under current state statute, Virginians with intellectual and developmental disabilities can remain in a Training Center, but do not have a right to remain in a Training Center of their choice. The Judge affirmed in his comments that a right to remain in a particular institution does not exist and that the “choice” to remain in a Training Center should not preclude the Commonwealth from closing a particular facility (such as the Northern Virginia Training Center or the Central Virginia Training Center). It is also important to note that a "right to remain" in a state-operated institution does not exist in Federal law.

Judge Gibney said he will forward some proposed language to the lawyers next week for review. He said he would also consider proposed language drafted by the Commonwealth of Virginia and the U.S. Department of Justice. Virginia’s Assistant Attorney General said the Governor could review final language in two weeks.

Be an Arc Ally - Donate to The Arc

The Arc of New Mexico is a statewide, non-profit agency that was born 56 years ago as a grassroots movement of families working vigilantly to create services for children and adults with disabilities who were being denied opportunities to receive an education, to work and to participate in their communities.

The Arc works on behalf of individuals with disabilities and their families every day to ensure that they have the support to participate in and contribute to their communities. The Arc serves as the Corporate Guardian for over 180 individuals, administers Special Needs Trusts for over 400 individuals and helps over 50 individuals with their Social Security Benefits in our Representative Payee Program. We also serve hundreds of people with disabilities and their families through our Self-Advocacy Programs and our Southern New Mexico Office located in Anthony, NM.

The Arc of New Mexico depends on public donations to sustain our work. You can make a one-time gift or a recurring gift. [Make a donation now](#) to support our mission to benefit all individuals with intellectual and developmental disabilities and their families in New Mexico.

A memorial gift is a beautiful and lasting tribute for a loved one or to a family as an expression of sympathy. Family and friends can be recognized with a gift in their honor. This might be for a special occasion such as a birthday, anniversary, holiday, wedding, retirement, etc.

THANK YOU

BANK OF THE WEST - GOLD SPONSOR - \$7,500

UNITED HEALTHCARE – BRONZE SPONSOR - \$2,500.